

How long will a loved one live? It's difficult to hear, but harder not to know

September 25 2023, by Lysanne Lessard, Amy T. Hsu, Peter Tanuseputro and Sampath Bemgal



Credit: AI-generated image ([disclaimer](#))

Planning for the future is difficult for people living with a life-limiting illness. Clinicians, based on their experience, can offer broad estimates of survival—in days to weeks, weeks to months, or months to years. However, patients and their care partners often want greater precision

when arranging or making decisions about their care.

An accurate prediction of survival can enable earlier conversations about preferences and wishes at the [end of life](#), and earlier introduction of palliative care.

However, even for an experienced clinician, [estimating the life expectancy](#) of a patient with a serious illness [is challenging](#). It requires large amounts of data and an understanding of the relationship between the patient's baseline health, the complexity of their medical condition and how they respond to or progress with treatment. This is where predictive algorithms could help.

A tool for timely conversations and planning

[RESPECT \(Risk Evaluation for Support: Predictions for Elder life in their Communities Tool\)](#) is a [risk communication tool](#) powered by prediction algorithms that estimate individuals' survival—that is, how long someone will live. It was developed by the Project Big Life Research Team and validated [using health-care data collected on nearly one million older adults who received home and community care](#) or nursing home care in Ontario.

RESPECT was designed with [patients'](#) information needs in mind, and with the intention of empowering patients and their care partners. By providing patients with data on the survival and experiences of other individuals who had similar disease journeys, the tool can help patients understand their own illness trajectory, have earlier conversations about their preferences and wishes, and advocate for the support they need.

A tool for patients, care partners and clinicians

[RESPECT](#) launched publicly on [ProjectBigLife.ca](#) in July 2021. [ProjectBigLife.ca](#) is home to several health calculators developed by the research team as a means of translating data and evidence into tools that can help Canadians think about their health and plan for their care.

Using the responses to 17 questions about their health and ability to care for themselves, RESPECT provides an estimate of a person's survival based on information gathered on people who have similar characteristics. Older adults, their care partners and [health care professionals](#) who are uncertain about the [life expectancy](#) of someone living with a critical illness can use the calculator to gain a better understanding of their decline.

Beyond life expectancy, RESPECT reports measures of functional decline—for example, whether the patient is able to get around their house and engage in activities of daily living, like bathing and cooking, without any assistance.

RESPECT Calculator Results: Reference Guide for People with Severe Frailty (Profile 2)

1 About This Reference Guide

This guide includes results from the RESPECT algorithm for people who meet criteria for Profile 2, using logic from the interRAI-HC assessment. The calculated risk represents the experience of people in Ontario, Canada, who received home care between 2018 and 2019.

2 People Who Fit Profile 2

The results in this report are based on the lived experiences of home care clients in Ontario.



97%

require extensive assistance with instrumental activities of daily living (IADLs) - things done every day to take care of themselves and their home (such as buying groceries, making meals, and cleaning the home)



63%

require extensive assistance with activities of daily living (ADLs) - things done to take care of physical needs (such as eating, using the bathroom, dressing, and being able to move around or walk without help)



92%

have experienced more difficulties taking care of physical needs in the last 3 months (such as needing help in the bathroom or needing support with walking)



51%

have experienced more difficulties making decisions about daily activities (such as what to eat, what to do, and what to wear) in the last 3 months

A patient can use the information in the RESPECT personalized report to discuss their care needs with their care partners and health-care providers.

Credit: RESPECT Research Team

A patient can use this information to discuss their care needs with their care partners and health-care providers. Similarly, health-care providers can use this tool to discuss with their patient what can be expected as the patient approaches the end of life, and plan for the supports that their patient may need.

RESPECT is also actively used in Ontario's retirement homes and nursing homes. Many residents in these settings have a life expectancy of less than two years. Earlier conversations about the older person's goals and wishes for their remaining life can enable the care team to provide the best quality of life and care for the individuals under their care.

Sustainable infrastructure

One of the goals of RESPECT is to provide sustainable infrastructure to study, learn and improve how we use predictive algorithms for end-of-life care.

Despite the benefits that are emerging from the early uses of RESPECT, many questions remain about when and how it can be most appropriately used. For example, poor numerical literacy—that is, a person's understanding of numbers, mathematics and statistics—could lead to misinterpreting the estimate provided by RESPECT. While the resources supporting RESPECT were co-developed with patients and their care partners, more research is still needed to reduce such potential harms.

3 Life Expectancy For People who Fit Profile 2

People with similar responses lived another 4.5 months on average



Of 100 people with similar responses:



The average life expectancy represents the experience of most people in this group. Some people may live longer or shorter.

4 1-Year Mortality For People Who Fit Profile 2



Of 100 people with similar responses: 72 died within 1 year
28 lived past 1 year

Disclaimer: These risk estimates are based on the experiences of home care clients between 2018-2019 and may differ from results presented on the RESPECT web calculator (www.projectbiglife.ca/elder-life-home) which was built on data between 2007-2014. Additionally we grouped clients into 1 of 5 groups, the web calculator provides more personalized risk estimates according to 61 groups. These predictions are based on similar people but a person may live longer or shorter. These predictions are meant to help plan and make decisions.

RESPECT personalized report provides an estimate of a person’s survival based on information gathered on people who have similar characteristics. Credit: RESPECT Research Team

To ensure we optimize the benefits that can be gained from prediction algorithms like RESPECT, clinical epidemiologists Douglas Manuel and Justin Presseau, along with the co-authors of this article, have created the RESPECT Learning Health System—a network of care partners,

researchers and health-care professionals collaborating to address these challenges. We combine research and practice to sustainably study, learn and improve end-of-life care and experience through predictive algorithms.

Identification is just the first step

Only [58 percent of people who die in Canada](#) receive some form of palliative care prior to death. Few (13 percent) are able to die at home with the support of palliative home care.

In deepening our understanding of frailty and decline, RESPECT may help clinicians, patients and their care partners be prepared for a [poor prognosis](#) and help develop a personalized plan for their care.

However, to improve end-of-life care delivery in Canada and enable Canadians to die with dignity, more investment is still needed within our formal health-care system to meet the need of individuals at the end of life.

This article is republished from [The Conversation](#) under a Creative Commons license. Read the [original article](#).

Provided by The Conversation

Citation: How long will a loved one live? It's difficult to hear, but harder not to know (2023, September 25) retrieved 23 June 2024 from <https://medicalxpress.com/news/2023-09-difficult-harder.html>

<p>This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.</p>
--